



Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions

Bridging the gaps between **health, social and local services** to improve care of people living with rare and complex conditions

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*The serious unmet social needs of people with a rare disease and their families affect their dignity, autonomy and other **fundamental human rights** expressed in the Universal Declaration of Human Rights and in the UN Convention of the Rights of Persons with Disabilities*

# The needs of people living with rare diseases require coordinated multidisciplinary care

In most countries the care pathways are not structured

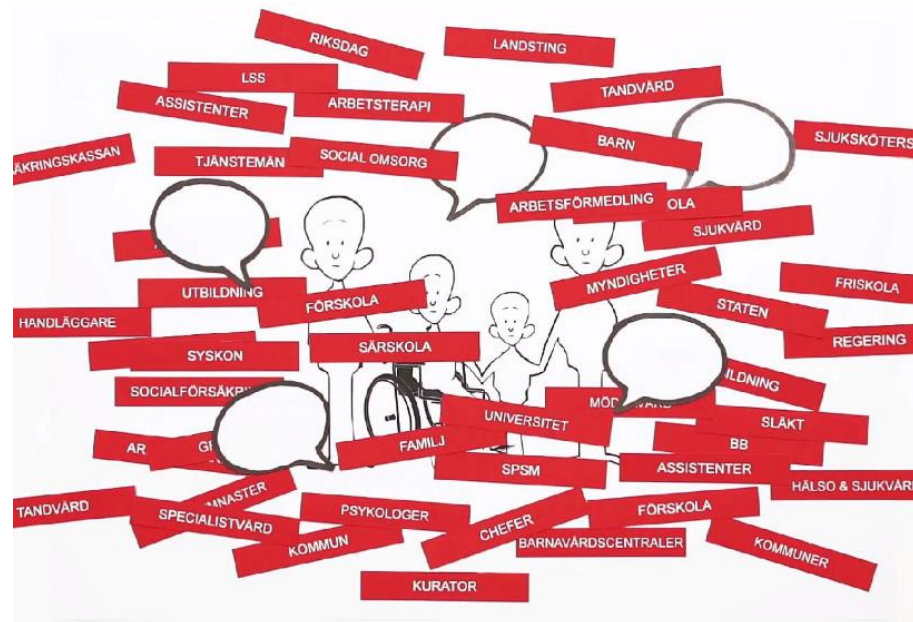


Image used for illustration purposes. Source: [Nationella Funktionen Sällsynta Diagnoser](#), Sweden

## European Commission Expert Group Recommendations to Support the Incorporation of Rare Diseases into Social Services and Policies (2016):

***«4. MS should promote measures that facilitate multidisciplinary, holistic, continuous, person-centred and participative care provision to people living with rare diseases, supporting them in the full realisation of their fundamental human rights.»***

**Unanimously adopted by representatives of all EU Member States**

[http://ec.europa.eu/health/rare\\_diseases/docs/recommendations\\_socialservices\\_policies\\_en.pdf](http://ec.europa.eu/health/rare_diseases/docs/recommendations_socialservices_policies_en.pdf)

## Next Step

# Moving from the recommendations to the implementation

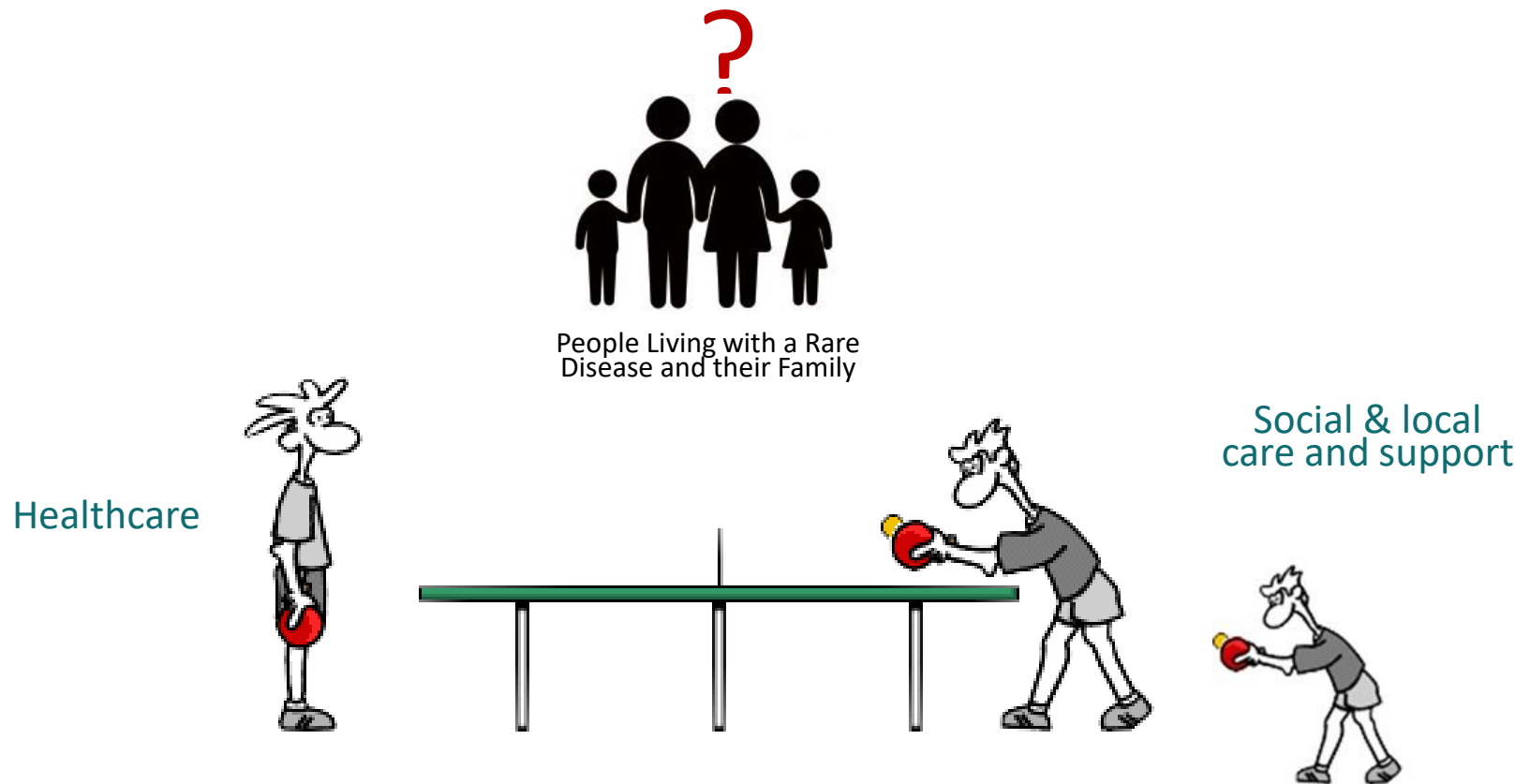


2015-2018

Bridging the gaps between **health**, **social** and **local services** to improve care of people living with rare and complex conditions



# The dilemma



# Project Overview

## **Call for proposals from EC DGEMP (2014) - “Social policy innovation”**

- Focus on one stop shop services & case handlers
- Over 200 projects submitted - 7 selected
- INNOVCare is the only project on health/disability and with European scope

**Time frame:** 36 months - 01/10/2015 to 30/09/2018

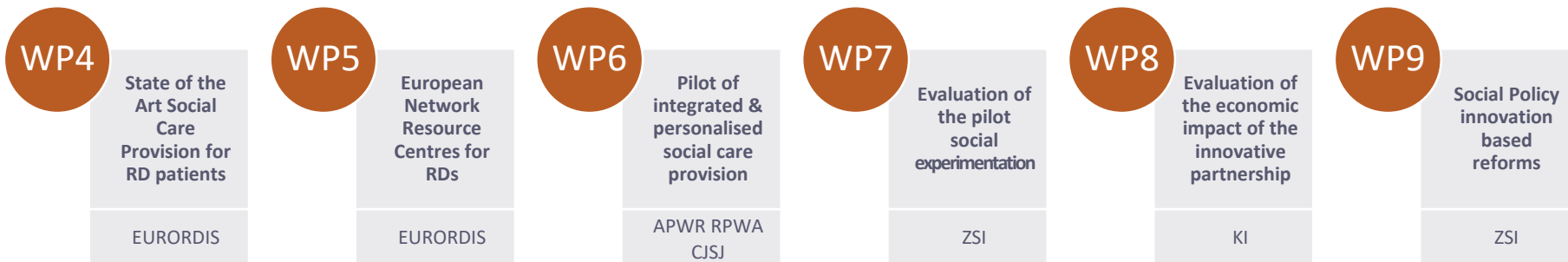
## **Consortium:**

- **8 partners, 6 countries** - Spain, France, Slovenia, Romania, Austria, Sweden
- Main Applicant: MSSSI Ministry of Health and Social Affairs – Spain

**Total budget:** 1 994 414.72€ (EC co-funding 80%)



# Project Structure



WP1 Coordination (MSSSI, Finovatis)  
 WP2 Evaluation (IER)  
 WP3 Communication & Dissemination (EURORDIS)

## Main Applicant

**MSSSI** Ministry of Health and Social Affairs - Spain - Aitor Aparicio García

## Co-Applicants

**Finovatis** – France - David Koubi

**IER** Inštitut za Ekonomska Raziskovanja – Slovenia – Valentina Rupel

**EURORDIS** – France – Raquel Castro

**APWR RPWA** Asociatia Prader Willi din Romania (NoRo) – Romania – Dorica Dan

**CJSJ** Regional County Sălaj – Romania - Monica Avram

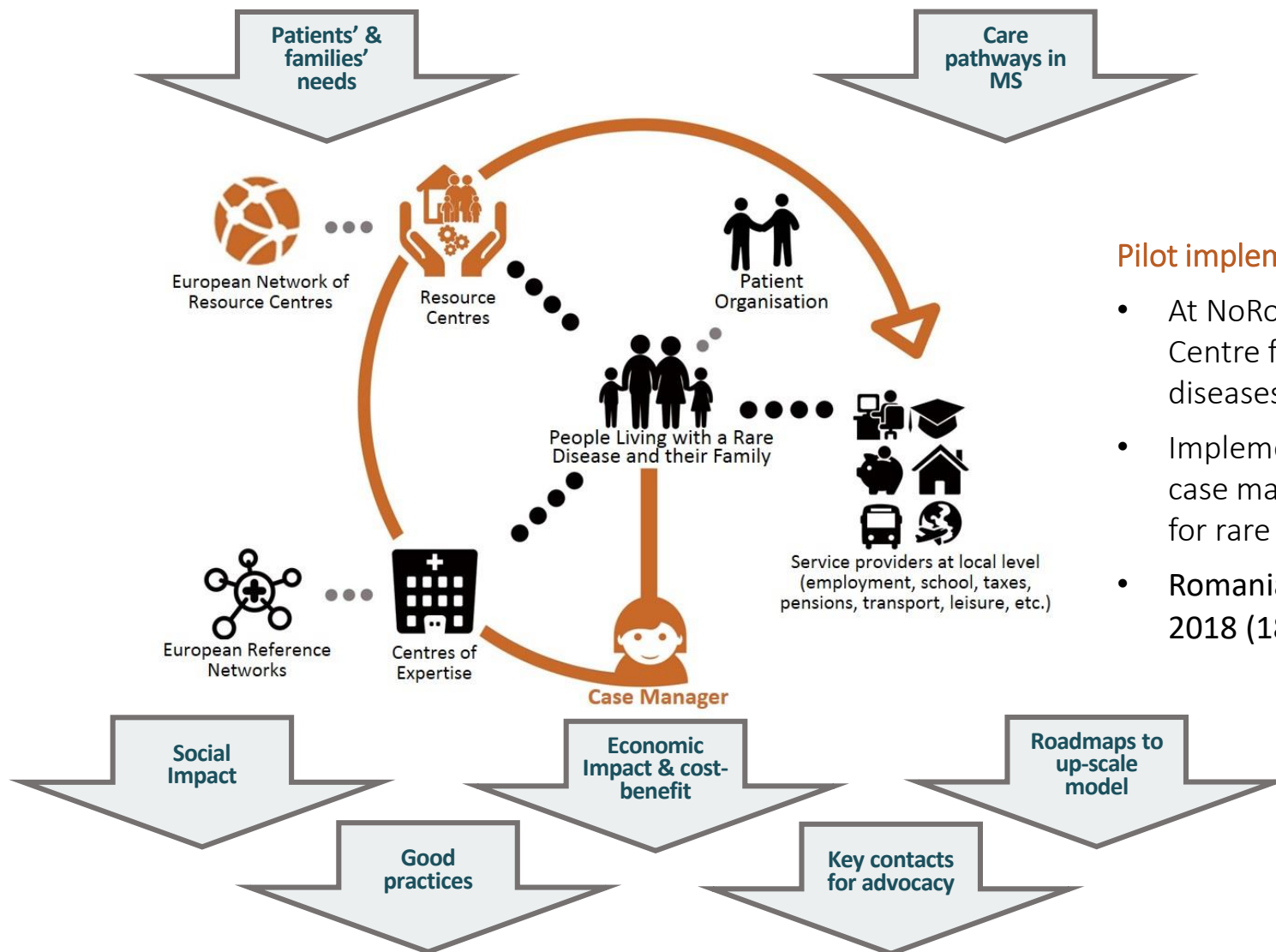
**ZSI** Zentrum für Soziale Innovation – Austria - Ursula Holtgrewe

**KI** Karolinska Institutet – Sweden - Peter Lindgren





# Project Concept



# Project Objectives

- **Assessment of social needs of people living with a RD in Europe & analysis of care models in MS** *(Austria, France, Hungary, Luxembourg, Romania, Spain, Sweden, UK);*
- **Proposal of an innovative care pathway:**
  - Implementation of a pilot in Romania
  - Evaluation of the socio-economic impact and cost-benefit analysis of the care model
  - Analysis of opportunities to upscale the model to other MS and beyond RDs
- **Creation of the European Network of Resource Centres & exchange of good practices between social services for rare diseases via workshops**
- **Strengthening partnerships between stakeholders:** creation of an Advisory Group with competent authorities

# Project Events

Date	Place	Event
8-9 Sept 2016	Gothenburg	Workshop on Improving Integrated Care for People Living with Rare Diseases and Complex Conditions
6-7 Oct 2016	Vienna	Workshop on Scaling Innovative Care Delivery for Rare Diseases & Complex Conditions
1-2 June	Cluj-Napoca	Workshop on Advancing Holistic & Innovative Care for Rare Diseases & Complex Conditions
12-13 April 2018	Oslo	Workshop on Creating a Sustainable Environment for Holistic & Innovative Care for Rare Diseases & Complex Conditions
Sept 2018	Brussels	Final conference

Details and presentations available at:  
<http://innovcare.eu/events/>

# Engaging with policy makers

## ✓ INNOVCare [Advisory Group](#)

- 17 representatives from 14 European countries
- National/regional competent authorities - mix of health and social
- Goal:
  - Promote better dissemination of the project to policy makers
  - Engage on up-scaling the pilot/similar model to their countries
  - Advisory Group will attend 3 workshops of the project

## ✓ Link to [Commission Expert Group on Rare Diseases](#)

## ✓ Link to [RD-Action project](#) (2015-2018), policy work package

# First Europe-wide survey on the social impact of rare diseases

# First Europe-wide survey on social impact of rare diseases

## Juggling care and daily life: The balancing act of the rare disease community

- Carried out via [Rare Barometer Voices](#)
- Over 3000 patients and carers involved
- 802 diseases, 42 countries
- Performed in 23 languages



# First Europe-wide survey on social impact of rare diseases

## Key results:

- Rare diseases have a serious impact on everyday life
- Significant time and care burden for patients & carers
- Impact on work-life: absence from work, stop or reduce professional activity, facing loss of income
- Patients and carers are badly informed about their rights
- Clear lack of communication between service providers
- Social services badly prepared to support people with a rare disease



[Report with analysis of key results and annex with full results](#)



# INNOVCare pilot of case management & evaluation of its social and economic impact

# INNOVCare pilot – NoRo Resource Centre

- Zalau, County of Salaj, Romania
- **One-stop-shop style of service**
- Recognised as social and healthcare provider *(Centre of Expertise for rare diseases)*
- **Providing services to patients** at local, county and national level



# INNOVCare pilot - Summary

## Regional case managers hired by NoRo resource centre Romania:

- To bridge the gaps in coordination between health, social and local services
- To reduce care burden for patients and families

## Time frame:

- 18 months, 03/2017 - 08/2018
- 9 months for each patient/family

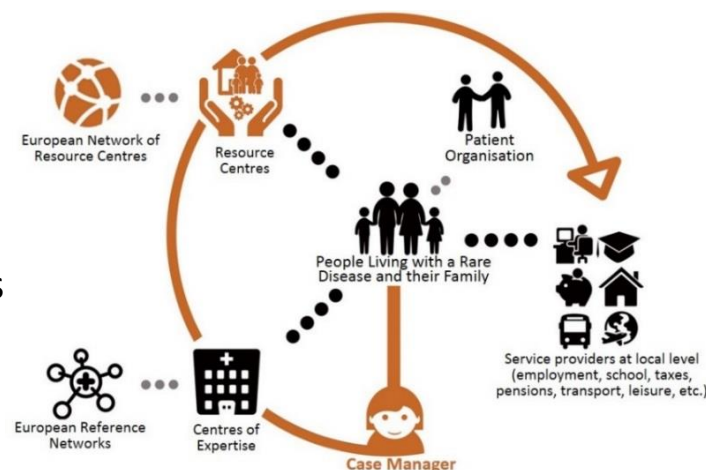
## Target population:

- Patients and families: rare diseases & complex conditions
- 118 cases
- Current beneficiaries of NoRo & new ones

## Geographical scope: region of Salaj, Romania

## Resources and service provision:

- Number of case managers employed: 4
- Nr. of simultaneous “cases” per case manager: 30
- Profile of case managers: 2 social workers, 1 lawyer and 1 special education teacher
- Service focused on key areas to have meaningful results



# INNOVCare pilot – Possible roles of the case manager

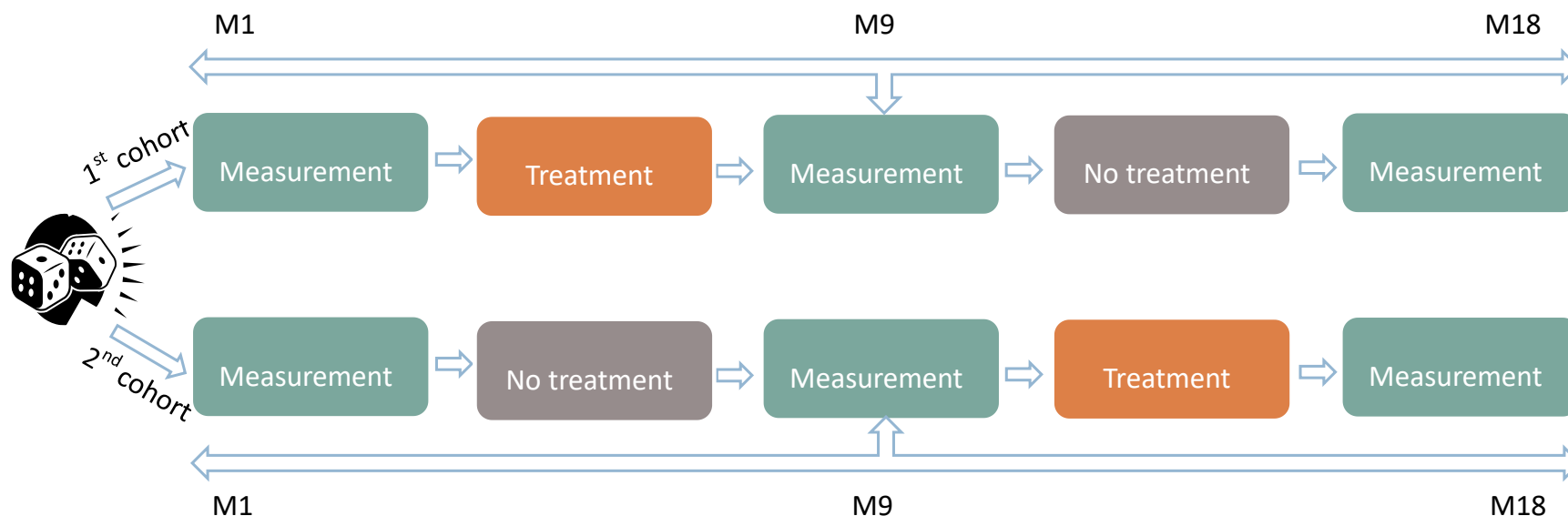
- **Single and stable point of contact**
- **Listen, inform, support and empower patients and families**
  - Providing knowledge/tools & informing about existing resources
  - Encourage health literacy and compliance to treatments
  - Relief the burden of care provision for patients and families
- **Assessment/monitoring of needs & being an observatory of those needs**
- **Holistic and patient-centred care planning and care co-ordination:**
  - Identify resources available in the territory - services and support
  - Referral to and speed up access to services and support
  - Simplify care pathways, ensure continuous support, support navigation for patients/families and professionals
- **Hub of information and knowledge**
- **Inform, support and empower professionals involved in care provision**
- **Facilitating coordination between services and networks of service providers**
- **Prevention of avoidable high risk situations & limit over-use of health services if not needed**
- **Develop working methods that support empowerment of patients and families**



# The INNOVCare evaluation design

*How does the INNOVCare intervention impact the quality of lives of those who benefit from it?  
What's the economic impact?*

## A basic two-condition repeated-measures design / rotation design



- **Sampling:** random proportionate stratified sampling, based on set of variables
- **Randomisation:** stratified random assignment - random allocation of participants into the 1st and 2nd cohorts based on set of variables; simple random allocation to the case managers;
- **Ex-post assessment of the randomisation procedure:** checking balance of the two cohorts

# RareResourceNet

European Network of Resource  
Centres for Rare Diseases

# RareResourceNet

*Advancing holistic high quality care and services for people living with rare diseases across Europe*



*Resource centres: a one stop shop style service designed for people living with a rare disease and their carers*

- **Complementary to health care and social services**
- **Holistic care and support**

<https://innovcare.eu/social-services/rareresourcenet/>

*The gathering of services in this network is possible following the mapping of specialised social services for rare diseases performed within the European Joint Action for Rare Diseases ([EURCERD Joint-Action](#), 2012-2015). RareResourceNet subscribes the [European Commission Expert Group Recommendations to Support the Integration of Rare Diseases into Social Services and Policies](#) (2016) & 2030 Agenda for Sustainable Development adopted by the United Nations (2015)*



# Find out more at innovcare.eu



Bridging the gaps between **health, social and local services** to improve care of people living with rare and complex conditions

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INNOVCare gives a voice to the social and everyday needs of people living with a rare disease and addresses the need for coordination between service providers in European Union Member States.

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[What We Do](#)





33%

1/3 of families see one member reduce or stop professional activity



33%

1/3 of families see one member reduce or stop professional activity



33%

1/3 of patients and families require assistance from a social worker



33%

1/3 of patients and families have difficulties to meet a social worker

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# Thank you

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